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MEASURING QUALITY OF LIFE IN PEDIATRIC CANCER PATIENTS:  
THE RELATIONSHIPS AMONG PARENTAL DEPRESSION, ANXIETY,  
STRESS, AND CONCORDANCE AMONG RATERS

by

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B.S. University of Florida, 2000

A thesis submitted in partial fulfillment of the requirements  
for the degree of Master of Science  
in the Department of Psychology  
in the College of Arts and Sciences  
at the University of Central Florida  
Orlando, Florida

Spring Term  
2005

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## ABSTRACT

Advancements made in the treatment of the physiological aspects of childhood cancer have resulted in a greater need to conceptualize the disease psychologically as a chronic illness that causes significant stress and requires ongoing adjustment. This study investigates the relationships among parental characteristics, child characteristics, and the quality of life of children diagnosed with cancer. Forty-seven mothers and sixteen fathers, as well as nineteen children diagnosed with cancer, completed measures of their own psychological functioning. Measures of the diagnosed children's quality of life also were completed. Mothers' ratings of their children's quality of life were found to be correlated positively with both fathers' and children's ratings. In addition, a significant relationship was found between mothers' depression and parenting stress and children's quality of life, as well as mothers' and fathers' anxiety and children's quality of life. Finally, mothers', fathers', and children's ratings of their own characteristics predicted significantly their ratings of children's quality of life. Overall, these results suggested the importance of examining the psychological characteristics of family members when assessing the quality of life of children with cancer.

This thesis is dedicated to all cancer victims,  
survivors, and their loved ones.

## ACKNOWLEDGMENTS

I would like to thank Dr. Kimberly Renk for her support, guidance, and encouragement throughout this process, without which none of this would have been possible. I would like to thank my committee members, Dr. Stacey Dunn and Dr. Jack McGuire, for their helpful suggestions and time commitment. Finally, I would like to thank the families who participated and acknowledge their enormous strength and generosity in contributing to this project at such a difficult time in their lives.

## TABLE OF CONTENTS

LIST OF TABLES.....	vii
CHAPTER ONE: INTRODUCTION.....	34
Quality of Life.....	34
Concordance in Ratings of Quality of Life.....	36
Parent and Child Psychological Symptoms and Ratings of Quality of Life.....	38
The Current Study.....	41
CHAPTER TWO: METHOD.....	42
Participants.....	42
Measures: Mothers and Fathers.....	44
Procedure.....	49
CHAPTER THREE: RESULTS.....	51
Overview of Analyses.....	51
Descriptive Information.....	52
Maternal, Paternal, and Child Quality of Life Ratings.....	53
Relationships Among Parental Characteristics and Quality of Life Ratings.....	53
Relationships Among Children's Characteristics and Quality of Life Ratings.....	54
Differences Between Sites.....	55
Type of Cancer, Time Since Diagnosis, and Child Age.....	55
Predicting Children's Quality of Life.....	56
CHAPTER FOUR: DISCUSSION.....	58
APPENDIX TABLES.....	34
REFERENCES.....	38

## LIST OF TABLES

Table 1. Correlational Analyses for Informants' Characteristics and Quality of Life Ratings ....	34
Table 2. Regression Analyses for Maternal Characteristics Predicting Children's Quality of Life .....	35
Table 3. Regression Analyses for Paternal Characteristics Predicting Children's Quality of Life .....	36
Table 4. Regression Analyses for Children's Characteristics Predicting Children's Quality of Life .....	37



## CHAPTER ONE: INTRODUCTION

Several studies have noted discrepancies in the ratings of quality of life experienced by children diagnosed with cancer when these ratings are provided by parents versus the children themselves (Boggs & Durning, 1998; Levi & Drotar, 1999; Parsons, Barlow, Levy, Supran, & Kaplan, 1999; Sawyer, Antoniou, Toogood, & Rice, 1999; Vance, Morse, Jenney, & Eiser, 2001; Varni, Katz, Colegrove, & Dolgin, 1995). Further, other studies have found that having a child with cancer can be related to negative effects on the well being of parents (Brown et al., 1992; Challinor et al., 1999; Kazak & Barakat, 1997; Kazak et al., 1997). Although parents of children with cancer may be experiencing significant difficulties in adjusting to their children's diagnosis, these parents often are called upon to provide information about how their children are functioning currently and to determine what is necessary for the continued improved functioning of their children. No study has investigated the relationships between the information provided by parents about their children's quality of life and their own functioning, however. As a result, the purpose of this study is to further validate the concordance among mothers, fathers, and children or adolescents diagnosed with cancer in their ratings of the quality of life experienced by these children and adolescents. In addition, this study will investigate the relationships among the ratings provided, parental characteristics (e.g., parental levels of depression, anxiety, parenting stress), and child characteristics (e.g., emotional and behavioral functioning, physical symptoms).

### *Quality of Life*

Great advancements have been made in the treatment of the physiological aspects of childhood cancer, with new treatments increasing survival rates of children with cancer

diagnoses to approximately 70 percent (Armstrong & Mulhern, 1999). This increase has resulted in many more children living with cancer today than just a few decades ago. As a result, health care providers have begun to focus on the psychosocial impact of cancer and its treatment on children and their families. Therefore, a more recent focus in pediatric oncology includes seeking a cure for cancer as well as assessing the costs of the treatments available (Feeny, Furlong, Mulhern, Barr, & Hudson, 1999).

In an effort to gather information about the psychosocial impact of cancer, measuring the quality of life of pediatric cancer patients has become one of the major foci when dealing with this population. Although many of the treatments being offered to pediatric cancer patients increase survival rates, they can result in overwhelming side effects, such as neuropsychological impairment, behavioral or psychological difficulties, elevated activity levels accompanied by mood swings and high levels of irritability, decreased reflexes, and decreases in fine motor coordination and speed (Armstrong & Mulhern, 1999). Depending on the side effects experienced, children undergoing treatment for cancer may experience a decrease in their quality of life. The term *quality of life* has been defined as a construct made up of several dimensions, including physical functioning, psychological state, social functioning, and physical discomfort (Ivan & Glazer, 1994). Due to the subjective nature of this construct, care needs to be taken in the process of obtaining accurate measurements.

Quality of life data can give a rich, quantifiable description of the impact of the disease, as well as its treatments, on the day-to-day functioning of child patients. These data can be used to provide doctors, patients, and their families with a wealth of information. For example, they can be used in clinical trials for the evaluation of different treatment modalities, such as surgery versus radiation plus chemotherapy, or in evaluating trials of expected therapeutic equivalence.

Since the information provided by quality of life measures quantifies the impact of treatment on the functioning of child patients, it can be an enormous asset for child patients, families, and medical professionals in making informed decisions about the benefits and costs of the various treatments available for different types of pediatric cancer (Bradlyn, Harris, & Spieth, 1995).

Two of the major questions concerning pediatric quality of life measures are how to elicit information from informants and who to elicit it from (Ivan & Glazer, 1994). A limitation to previous studies on the quality of life experienced by children with cancer is the heavy reliance on parental reports of children's functioning. The degree to which concordance exists and the interpretation of this concordance in health related quality of life (HRQOL) research are topics that have emerged only recently (Armstrong et al., 1999). Concordance between multiple informants providing information about children's emotional and behavioral functioning have been well-documented, however (e.g., Achenbach, McConaughy, & Howell, 1987; Duhig, Renk, Epstein, & Phares, 2000), and may lend valuable information to this developing research area.

### *Concordance in Ratings of Quality of Life*

A few studies have begun investigating the concordance between parents and their children or adolescents who have been diagnosed with cancer in their ratings of the quality of life experienced by these children (Boggs & Durning, 1998; Levi & Drotar, 1999; Parsons et al., 1999; Sawyer et al., 1999; Vance et al., 2001). For example, Levi and Drotar (1999) reported lower concordance in the ratings of quality of life provided by children with cancer and their parents than in ratings provided by children who did not have cancer and their parents. Further, Sawyer and colleagues (1999) found that parents of adolescents who were receiving treatment reported that the illness was having a greater impact on the adolescents' physical, social, and

school activities than was reported by the adolescents themselves. In both of these studies, a generic measure of quality of life was used, however. Such a generic measure can provide only limited information about specific concerns experienced by children and adolescents with cancer. Nonetheless, the lack of concordance found between parental and child ratings highlight the importance of investigating possible reasons for these differential ratings.

A study conducted by Parsons and colleagues (1999) began to examine the reasons for the lack of concordance between parental and child ratings of quality of life. These researchers identified an interaction between the amount of time since the child received treatment and the direction of the disagreement. The results of this study demonstrated that children who had a bone marrow transplant within the past six months reported doing better in all areas of functioning in comparison to the ratings provided by their parents. In contrast, when the amount of time since treatment was more than six months after a bone marrow transplant, the pattern reversed, with parents reporting higher scores in physical functioning, role function, and energy. These findings suggested that there is a complicated relationship in the concordance among raters.

Finally, different informants of a child or adolescent's quality of life may focus on different information when providing ratings. Other important findings of the study conducted by Parsons and colleagues (1999) suggested that children are capable of providing valid and reliable information about their own quality of life and that other informants appear to be better at describing what patients can do rather than how they are doing (Parsons et al., 1999). These findings also were supported by an ongoing study discussed in a chapter by Boggs and Durning (1998). This study found that only one out of three factors, that which measured physical functioning and restriction from normal routine, on the parent rated Pediatric Oncology Quality

of Life Scale correlated significantly with children's self-ratings. The ratings of children and their parents on the remaining two factors, which measured children's general emotional distress and response to current medical treatments, were not correlated significantly. Measures that assume parents can evaluate objectively what their children are feeling suggest that there is a transparency about children, giving parents access to children's "internal states". This approach also suggests that children disclose their feelings to their parents without providing information about their emotional adjustment or cognitive processing. These assumptions have not been supported by empirical research, however (e.g., Achenbach et al., 1987; Phipps, Dunavant, Deepthi, & Srivastava, 1999).

#### *Parent and Child Psychological Symptoms and Ratings of Quality of Life*

Several studies examining the relationship between parental psychological symptoms and ratings of children's emotional and behavioral problems have found an association between parental psychological symptoms (i.e., depression and anxiety) and biases in their ratings of their children's emotional and behavioral functioning (Fergusson, Lynskey, & Harwood, 1993; Mick, Santangelo, Wypij, & Biederman, 2000; Moretti, Fine, Haley, & Marriage, 1985; Najman et al., 2000). In general, these studies have suggested that mothers who are depressed or anxious tend to rate their children as experiencing higher levels of depression and behavior problems. Further, the reports of these mothers have been shown to be consistent with their children's own self-report. In contrast, these discrepancies have not been found in the ratings of mothers who are not depressed or anxious (Najman et al., 2000). Given these findings, it may be unrealistic to expect parents to provide reports about the psychological and behavioral characteristics of their children

or adolescents without exhibiting some bias in their reports that are likely due to their own psychological distress (Moretti et al., 1985).

In examining parental ratings of children's functioning, it is important to be able to recognize what factors potentially could bias ratings. In this way, these factors can be taken into account when assessing the validity of such ratings. Various explanations for why parents exhibiting psychological distress have a tendency to report greater levels of behavior problems in their children have been proposed. For example, it is possible that depressed parents may be projecting their own feelings onto their children and, thus, are more prone to be biased in their ratings (Moretti et al., 1985). Another possibility is the presence of a third, non-observed influence on parental psychological symptoms (e.g., depression) and parental reporting behaviors, such as that of family social background, parental education, and/or personality characteristics (Fergusson et al., 1993). Overall, the literature has suggested that parental psychological distress is related to a tendency for mothers to rate their children and adolescents as exhibiting greater levels of behavior problems and psychological dysfunction (Fergusson et al., 1993; Mick et al., 2000; Moretti et al., 1985; Najman et al., 2000). There is little information regarding the relationships of parental psychological symptoms and ratings of the quality of life exhibited by children and adolescents, however.

Relationships such as those noted between parental psychological symptoms and child behavior problems may be applicable to ratings of child quality of life as well. When faced with their child's cancer diagnosis, parents often respond with feelings of helplessness, fear, anger, guilt, and sadness. Some parents have been found to develop post-traumatic stress symptoms, as well as higher levels of anxiety and depression. These symptoms have been related directly to their child's cancer diagnosis and treatment course (Kazak & Barakat, 1997; Kazak et al., 1997).

In addition, there are many psychological adjustment issues that the child patient, family, and caregivers must face. The first issue faced is the adjustment to the initial diagnosis. In this early phase, parents may react with a significant amount of grief, anger, hostility, shock, and guilt. Also, some of the medical procedures can be frightening and anxiety provoking for both the parent and the child. These reactions may affect the ability of the parent to comprehend and follow along with the much needed medical regimen (Baider, Cooper, & De-Nour, 1996).

Once the diagnosis is established and treatment has begun, the patient and their families are faced with the task of trying to resume their lives with some sense of normalcy while, at the same time, dealing with the demands of the child's rigorous medical treatments. Financial issues also may be a concern in families, not only with regard to the medical costs, but also the many visits to the doctor and the long hospital stays that are sometimes required. To assist their children through these visits, parents may need to be absent from work (Baider et al., 1996). Differences between the parents' coping styles also may cause conflict. For example, if one parent is reserved and the other is asking questions and expressing emotions, this discrepancy can cause marital problems as well (Baider et al., 1996). The stresses of having a child or adolescent diagnosed with cancer can cause multiple problems within the family system at a time when the family needs to work together to ensure that the child patient is receiving the best care and support possible. Each of these factors may be related to parents' own experience of psychological symptoms. Due to the common practice of obtaining parental ratings in assessing the quality of life experienced by pediatric cancer patients, more research is needed to investigate the relationship of parental ratings, parental characteristics, and child characteristics.

### *The Current Study*

Measuring quality of life has become an important aspect in the treatment of pediatric cancer patients. There is limited information about the level of concordance between maternal and paternal ratings, as well as about the relationship between parent and child ratings of the quality of life experienced by children and adolescents diagnosed with cancer and their psychological symptoms. As a result, one purpose of the current study is to further validate the lack of concordance among mothers, fathers, and the children or adolescents themselves in their ratings of the quality of life experienced by children diagnosed with cancer. Another purpose is to investigate the relationships among ratings of quality of life, parental characteristics (e.g., depression, anxiety, parenting stress), and child characteristics (e.g., emotional and behavioral functioning, physical symptoms) using more specific scales to measure parental, as well as child, characteristics that may be related to quality of life ratings.

Based on the findings discussed earlier (Boggs & Durning, 1998; Levi & Drotar, 1999; Parsons et al., 1999; Vance et al., 2001), the first hypothesis is that high concordance will be found between mothers and fathers and low concordance will be found between parental and child ratings on the quality of life measure used in this study. A second hypothesis is that maternal and paternal depression, anxiety, and parenting stress will be correlated negatively with maternal and paternal ratings of quality of life in children and adolescents (e.g., Brown et al., 1992; Vance et al., 2001). A third hypothesis is that child self-reported levels of depression and anxiety will be correlated positively with parental self-reported levels of their own anxiety, depression, and parenting stress levels. Finally, maternal, paternal, and child characteristics will predict the respective ratings of quality of life provided by these informants.



## CHAPTER TWO: METHOD

### *Participants*

Participants were families who had a child diagnosed with cancer and who were receiving outpatient treatment through Florida Hospital's Children's Center for Cancer and Blood Diseases in Orlando, Florida, or All Children's Hematology and Oncology Clinic in St. Petersburg, Florida. There were 150 families approached for participation. Of those families that were approached, 47 mothers, 16 fathers, and 19 children returned completed packets of questionnaires. Studies assessing similar populations have reported return rates ranging from 2 percent to 71 percent for various family members and have reported difficulties such as refusals to participate and lack of time to complete the study questionnaires as barriers to securing participation (Sawyer et al., 1999; Theunissen et. al, 1998; Vance et al., 2001). It also should be noted that all the studies that assess quality of life in children with pediatric cancer in the current literature had at least one author that was associated directly with a medical school or hospital, possibly allowing for easier access to the population under study.

Of those who returned completed packets, there were 4 families that included packets from all three family members, 8 that included mother and father packets only, 14 families that included mother and child packets, and 1 family that included only father and child packets. It is believed that fewer fathers completed and returned their questionnaires as it was mothers who were attending medical appointments with their affected children generally. Unfortunately, many children were not eligible to participate because they were younger than 8-years of age (i.e., children were required to be 8-years of age or older to participate).

Mothers who participated in this study ranged in age from 20- to 50-years ( $M=34.3$ -years,  $SD=6.7$ -years). The majority of mothers who participated in this study were Caucasian (71.1%).

A small number of mothers were African American (13.3%), Hispanic American (13.3%), and Asian American (2.2%). Their children and adolescents ranged in age from 9-months to 19-years ( $M=8.3$ -years,  $SD=5.3$ -years). These children and adolescents had been coping with their diagnosis of pediatric cancer from 2 months to 112 months ( $M=25.6$  months,  $SD=26.0$  months). Children and adolescents varied in the type of cancer that was diagnosed and the stage of treatment that they were experiencing at the time of the study. Mothers reported diagnoses of Leukemia (50%), some form of brain tumor (20.5%), Hodgkin's Disease (11.4%), and other types of cancer (18.2%) for their children and adolescents.

Fathers who participated ranged in age from 27- to 47-years ( $M=37.9$ -years,  $SD=5.8$ -years). The majority of fathers who participated in this study were Caucasian (62.5%). A small number of fathers were African American (18.8%), Hispanic American (6.3%), Asian American (6.3%), and 6.3 percent identified themselves as "other". Their children and adolescents ranged in age from 2-years to 15-years ( $M=8.1$ -years,  $SD=3.8$ -years). These children and adolescents had been coping with their diagnosis of pediatric cancer from 2 months to 112 months ( $M=29.4$  months,  $SD=30.6$  months). Children and adolescents varied in the type of cancer that was diagnosed and the stage of treatment that they were experiencing at the time of the study. Fathers reported diagnoses of Leukemia (50%), some form of brain tumor (28.6%), Hodgkin's Disease (7.1%), and other types of cancer (14.3%) for their children and adolescents.

Children who participated ranged in age from 8- to 19-years ( $M=13.7$ -years,  $SD=2.7$ -years). The majority of children who participated in this study were Caucasian (68.4%). A small number of children were African American (10.5%), Hispanic American (15.8%), and Asian American (5.3%). These children and adolescents had been coping with their diagnosis of pediatric cancer from 4 months to 112 months ( $M=38.0$  months,  $SD=31.7$  months). Children and

adolescents varied in the type of cancer that was diagnosed, with 38.9 percent reporting a diagnosis of Leukemia, 5.6 percent reporting a diagnosis of some form of brain tumor, 27.8 percent reporting a diagnosis of Hodgkin's Disease, and 27.8 percent reporting other types of cancer.

Additional attempts at data collection were made without success. These attempts included posting the study on a national cancer website, mailing over 50 fliers eliciting participation from pediatricians' offices in Central Florida, and contacting other outpatient oncology clinics located in Lakeland, Florida, and Tampa, Florida.

#### *Measures: Mothers and Fathers*

*Quality of Life.* Mothers and fathers completed the Pediatric Oncology Quality of Life Scale (POQOLS; Goodwin, Boggs, & Graham-Pole, 1994), which was used to measure children's quality of life. This is a 21-item measure that provides three factor scores (physical function and role restriction, emotional distress, and reaction to current medical treatment) and a total score. The total score was used in the analyses. This measure was chosen based on its specific application to cancer and its adequate psychometrics in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .85$ ). In this study, reliabilities also were found to be within the acceptable range for both mothers and fathers ( $\alpha = .91$  and  $\alpha = .91$ , respectively).

*Children's Emotional and Behavioral Functioning.* The Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2000; Achenbach & Rescorla, 2001) was used to measure children's emotional and behavioral functioning. Mothers and fathers completed the version consistent with the age of their child or adolescent (i.e., 1.5- to 5-years or 6- to 18-years). On

both versions, standardized T scores are provided for Internalizing (e.g., depression, anxiety, withdrawal), Externalizing (e.g., acting out, hyperactivity, aggression), and Total dimensions of emotional and behavioral problems experienced by children and adolescents. Scores for Internalizing and Externalizing Problems were used in this study. This measure was chosen based on adequate psychometrics found in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .89$  to  $.97$ ). In addition, the CBCL is the most widely used measure for assessing emotional and behavioral functioning in children and adolescents.

*Children's Physical Symptoms.* A Symptoms Checklist was developed for this study and used to measure children's specific cancer-related symptoms. Items were taken from sources describing the most common symptoms reported by children who have been diagnosed with cancer. Given that this measure was created for this study, a factor analysis was conducted. The factor analysis revealed that there were two items that were not reliable and did not load onto any one factor. Therefore, the two items were discarded, and all analyses were conducted on the remaining 13 items. Thus, the possible range in scores was from 13 (minimal symptoms) to 52 (many symptoms). Although three factor scores were derived, as noted below, a total score was calculated by summing the scores from the three factors in an effort to increase reliability.

As part of the factor analysis, the appropriate number of factors was determined using chi-square analysis, which tested inferentially the likelihood of having  $p$  factors in the given model, and using a scree plot analysis. Both methods indicated that an appropriate solution would be composed of three factors. As a result, an iterative principal-axis factor analysis, utilizing a squared multiple correlation communality estimate and oblique rotation, was used to extract three factors. The first factor, labeled *Physical Side-Effects*, consisted of Nausea, Fatigue, Throwing-up, Sleep Difficulty, Fevers, Poor Appetite, Painful Procedures, Increased

Sleep, and Crankiness (loadings of 0.72, 0.75, 0.82, 0.52, 0.76, 0.63, 0.65, 0.59, and 0.54, respectively). The second factor, labeled *Pain*, consisted of Physical Pain and Headaches (loadings of 0.71 and 0.90, respectively). The third factor, labeled *Cognitive Symptoms*, consisted of Poor Balance and Poor Concentration (loadings of 0.85 and .59, respectively). Each of these factors demonstrated adequate internal consistency (Cronbach alpha coefficients of 0.87, 0.66, and 0.66, respectively). As will be noted later, the scores from this measure were correlated significantly and meaningfully with several other measures used in this study.

*Parents' Psychological Symptoms.* The Beck Depression Inventory-Second Edition (BDI-II; Beck, Steer, & Brown, 1996) was used to measure parents' own depressive symptoms. The BDI-II is a 21-item self-report instrument for measuring the severity of depressive symptoms in adults. It was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorders listed in the DSM-IV and DSM-IV-TR (APA, 2000). Each item is rated on a 4-point scale from 0 to 3, with a total score ranging from 0 (minimal) to 63 (severe). This measure was chosen based on adequate psychometric properties in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .93$ ). In this study, reliabilities also were found to be within the acceptable range for both mothers and fathers ( $\alpha = .93$  and  $\alpha = .90$ , respectively).

The Beck Anxiety Inventory (BAI; Beck & Steer, 1990) was used to measure parents' own anxiety. The BAI is a 21-item scale that measures the severity of anxiety in adults. It was constructed to measure symptoms of anxiety that are minimally shared with those of depression. The items are rated on a 4-point scale from 0 to 3, with a total score ranging from 0 (minimal) to 63 (severe). This measure was chosen based on adequate psychometric properties in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .94$ ). In this study,

reliabilities also were found to be within the acceptable range for both mothers and fathers ( $\alpha = .92$  and  $\alpha = .93$ , respectively).

*Parenting Stress.* The Parenting Stress Inventory (PSI; Abidin, 1995) was used to measure parenting stress. The PSI is a 36-item Likert-type measure that contains three subscales (i.e., Parental Distress, Parent-Child Dysfunctional Interaction, and Difficult Child) and a total stress score. The total score was used in this study, with a lower score indicating less stress. This measure was chosen based on adequate psychometric properties in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .90$ ). In this study, reliabilities also were found to be within the acceptable range for both mothers and fathers ( $\alpha = .96$  and  $\alpha = .96$ , respectively).

*Demographic Characteristics.* Finally, a demographics questionnaire assessed parents' own demographic variables as well as the treatment and demographic variables of their children.

#### *Measures: Children*

*Quality of Life.* A children's version of the Pediatric Oncology Quality of Life Scale (POQOLS; Goodwin et al., 1994) was used to measure children's report of their own quality of life. This 21-item self-report measure, created originally for parental ratings of quality of life, was reworded for this study into the first person in order to assess children's perceptions of their own quality of life. The total score was used in the analyses. In this study, reliability for the child scores of the POQOLS was in the acceptable range ( $\alpha = .83$ )

*Children's Emotional and Behavioral Functioning.* The Children's Depression Inventory (CDI; Kovacs, 1980) was used to measure children's own symptoms of depression. This 27-item self-report inventory contains five factors (i.e., Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia, and Negative Self Esteem) and a total score (a standardized T score)

derived from the five factor scores. The total score was used in the analyses, with higher scores indicating higher levels of depression. This measure was chosen based on adequate psychometric properties in previous studies, including reliabilities reported in the acceptable range ( $\alpha = .86$ ). In this study, reliability for the CDI was in the acceptable range ( $\alpha = .81$ ).

The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1978) was used to measure children's own symptoms of anxiety. This 37-item self-report inventory contained three factors (i.e., Physiological Anxiety, Worry and Oversensitivity, and Concentration Anxiety). A total score (a standardized T- score) derived from the three factor scores was used, with higher scores indicating higher levels anxiety. This measure was chosen based on adequate psychometrics found in previous studies, with reliabilities reported in the acceptable range ( $\alpha = .82$ ). In this study, reliability for the RCMAS was relatively low ( $\alpha = .30$ ), however.

The Youth Self Report (YSR; Achenbach & Rescorla, 2001) was used to measure children's emotional and behavioral functioning. This measure provides normalized T scores for Internalizing Problems, Externalizing Problems, and Total Problems scales, as well as for eight syndrome scales (e.g., withdrawn, somatic complaints, anxious/depressed). Scores for Internalizing and Externalizing Problems were used in this study. This measure was chosen based on adequate psychometric properties found in previous studies with reliabilities reported in the acceptable range ( $\alpha = .90$  to  $.95$ ). It should be noted that this measure is in the same family of measures as the CBCL, discussed previously.

*Children's Physical Symptoms.* A Symptoms Checklist was used to measure children's specific cancer-related symptoms. This checklist was developed for this study and was identical to the one created for the parents, except that it was reworded into first person. Items were taken

from sources describing the most common symptoms reported by children who have been diagnosed with cancer. The same items were used for children and adolescents as for parents so that scores were consistent across children and adolescents and their parents. The possible range of scores was between 13 (minimal symptoms) and 52 (many symptoms). Reliability for the symptoms checklist was within the acceptable range ( $\alpha = .86$ ).

### *Procedure*

Interested families were contacted initially by a nurse practitioner or medical assistant at one of the two respective sites (due to HIPAA) in an effort to secure their participation in the study. At that time, the families were given a brief description of the study and the requirements for participation. In the event that the family agreed to participate, they were asked to complete consent forms for their own participation and permission forms for their children (i.e., if their children were 8-years of age or older). Upon completion of appropriate consent forms, a researcher met with the interested family members at their respective site so that they could receive a packet of questionnaires for completion.

If both parents were not in attendance, one packet was provided to the parent in attendance, and a separate packet was provided for the absent parent so that the packet could be taken home for completion. In many cases, it was discovered that it was inconvenient for the family members to complete the packet of questionnaires on site due to the nature of the appointment that they were having that day. In these instances, the families were allowed to take their packets home for completion and were requested to bring their completed packets back to their next scheduled appointment or to return them by mail in a prepaid envelope provided by one of the researchers. In an effort to increase return rate of the packets, the families received



follow-up reminders from their nurse practitioner during their next appointment after receiving the packets. In addition, the researcher gave reminder phone calls to those families who gave their phone numbers on the consent forms if the packets were not returned within two weeks and sent letters to those families who had not returned their packets within one month. A debriefing form was included in all packets.

## CHAPTER THREE: RESULTS

### *Overview of Analyses*

To put the results of this study into context, the means and standard deviations of scores on each measure were calculated and compared. Correlations were calculated to examine the relationships among the maternal, paternal, and child ratings provided on the POQOLS. In addition, t-tests were used to assess for differences in ratings across mothers, fathers, and children. Although correlations describe the relationship between variables, they do not provide information about significant differences between variables. As a result, both correlational analyses and t-tests were used. Further, correlations also were used to examine the relationships of parental characteristics (e.g., depression, anxiety) to parental ratings of quality of life and the relationship of child characteristics (e.g., depression, anxiety) to child ratings of quality of life.

Due to the insufficient number of data from all three family members within each family ( $n = 4$ ), the initially proposed analyses of covariance were unable to be included. As an alternative, hierarchical regression using forward entry was used to assess the predictive value of mothers', fathers', and children's characteristics on their respective quality of life ratings. For the regression analyses, the criterion variables were the respective quality of life ratings provided by parents and children. The predictor variables were depression, anxiety, and parenting stress for the parents, and depression, anxiety, internalizing problems, externalizing problems, and physical symptoms for the children.

### *Descriptive Information*

Mothers reported that they were experiencing minimal symptoms of depression ( $M = 13.33$ ,  $SD = 11.57$ ), mild symptoms of anxiety ( $M = 9.04$ ,  $SD = 9.49$ ), and significant levels of parenting stress ( $M = 81.69$ ,  $SD = 29.95$ ). On average, mothers reported that their children and adolescents were experiencing nonclinical levels of internalizing ( $M = 55.24$ ,  $SD = 11.09$ ) and externalizing ( $M = 51.61$ ,  $SD = 12.33$ ) behavior problems, minimal levels of physical symptoms ( $M = 24.14$ ,  $SD = 8.94$ ), and some impairment in their quality of life ( $M = 84.49$ ,  $SD = 24.46$ ).

Similarly, fathers reported that they were experiencing minimal symptoms of depression ( $M = 9.31$ ,  $SD = 9.47$ ), minimal symptoms of anxiety ( $M = 7.00$ ,  $SD = 9.01$ ), and significant levels of parenting stress ( $M = 67.31$ ,  $SD = 22.51$ ). On average, fathers reported that their children and adolescents were experiencing nonclinical levels of internalizing ( $M = 51.80$ ,  $SD = 14.77$ ) and externalizing ( $M = 49.53$ ,  $SD = 12.40$ ) behavior problems, minimal levels of physical symptoms ( $M = 21.25$ ,  $SD = 7.75$ ), and some impairment in their quality of life ( $M = 90.06$ ,  $SD = 22.09$ ).

Finally, children and adolescents reported that they were experiencing minimal symptoms of depression ( $M = 11.95$ ,  $SD = 9.22$ ), mild symptoms of anxiety ( $M = 15.16$ ,  $SD = 8.29$ ), nonclinical levels of internalizing ( $M = 58.94$ ,  $SD = 11.63$ ) and externalizing ( $M = 52.24$ ,  $SD = 10.66$ ) behavior problems, mild levels of physical symptoms ( $M = 29.31$ ,  $SD = 9.76$ ), and some impairment in their quality of life ( $M = 79.63$ ,  $SD = 20.21$ ).

### *Maternal, Paternal, and Child Quality of Life Ratings*

Due to limitations in available cross-informant pairs, only the correspondence between mothers and fathers ( $n=12$ ) and mothers and children ( $n=18$ ) was examined. Mothers' and fathers' ratings of children's quality of life on the POQOLS were correlated positively and significantly ( $r = .72, p < .009$ ). Mothers' and children's ratings of children's quality of life on the POQOLS also were correlated positively and significantly ( $r = .71, p < .009$ ). Furthermore, t-tests revealed that both the mothers' and fathers' ratings,  $t(df = 11) = -.86, p < .41$ , and mothers' and children's ratings,  $t(df = 17) = -.36, p < .73$ , were not significantly different from each other.

### *Relationships Among Parental Characteristics and Quality of Life Ratings*

The relationships among parental characteristics (i.e., depression, anxiety, and parenting stress) and parental quality of life ratings were examined using correlational analyses. Results are presented in Table 1. The analyses revealed a significant relationship between parental depression and parental ratings of children's quality of life for mothers ( $r = -.38, p < .01$ ) but not for fathers ( $r = -.49, p < .06$ ), a significant relationship between parental anxiety and parental ratings of children's quality of life for both mothers ( $r = -.49, p < .001$ ) and fathers ( $r = -.59, p < .02$ ), and a significant relationship between parenting stress and parental ratings of children's quality of life for mothers ( $r = -.31, p < .04$ ) but not for fathers ( $r = -.46, p < .07$ ). The low number of fathers who participated in the study may have contributed to the lack of significant findings with regard to fathers' ratings.

The relationships among parental characteristics (i.e., depression, anxiety, and parenting stress) and children's ratings of their own characteristics (e.g., depression, anxiety) and quality of life also were examined using correlational analyses. These results also are presented in Table 1. Children's depression was not related significantly to their mother's depression ( $r = .22, p < .41$ ), anxiety ( $r = .24, p < .36$ ), or parenting stress ( $r = .34, p < .19$ ). Similarly, children's anxiety was not related significantly to their mother's depression ( $r = -.01, p < .97$ ), anxiety ( $r = .12, p < .66$ ), or parenting stress ( $r = .19, p < .48$ ). In relation to their father's characteristics, children's depression was related significantly to their father's parenting stress ( $r = .97, p < .006$ ) but not to their father's depression ( $r = .46, p < .44$ ) or anxiety ( $r < .33, p < .58$ ). Children's anxiety was not related significantly to their father's depression ( $r = -.42, p < .48$ ), anxiety ( $r = -.45, p < .45$ ), or parenting stress ( $r = .35, p < .56$ ). Children's quality of life ratings were not related to maternal characteristics; however, these ratings were related to father's depression and anxiety ( $r = -.92, p < .05$ , and  $r = -.96, p < .05$ , respectively). Finally, children's self-report of their externalizing behavior problems was related to mothers' parenting stress ( $r = .51, p < .05$ ). Children's self-report of their internalizing and externalizing behavior problems was related to fathers' parenting stress ( $r = .92, p < .05$ , and  $r = .93, p < .05$ , respectively).

#### *Relationships Among Children's Characteristics and Quality of Life Ratings*

The relationships among children's characteristics (i.e., depression, anxiety, internalizing problems, externalizing problems, and physical symptoms) and their own quality of life ratings were examined using correlational analyses. These results are presented in Table 1. The analyses revealed a significant relationship between children's ratings of their own quality of life

and their own depression, internalizing problems, and physical symptoms ( $r = -.67, p < .01$ ;  $r = -.54, p < .03$ ; and  $r = -.66, p < .01$ , respectively).

### *Differences Between Sites*

Because data was collected at two different sites, the sites were compared using independent t-tests to assess for differences in means across all variables included in the study. For maternal variables, differences were found across the two sites for maternal ratings on the symptoms checklist,  $t(df = 44) = 2.01, p < .05$ . This variable was not used in the regression analysis examining mothers' variables, however. For paternal variables, differences were found across the two sites for paternal ratings on the quality of life measure,  $t(df = 14) = -2.22, p < .04$ . As a result, the fathers' site was controlled in the regression analysis predicting paternal quality of life ratings. No differences were found across the two sites for child variables.

### *Type of Cancer, Time Since Diagnosis, and Child Age*

Because children with several types of pediatric cancer were included in this study, a one-way analysis of variance (ANOVA) comparing the quality of life scores across the different cancer diagnoses was performed. The results revealed that the differences in quality of life scores were not significant,  $F(3,40) = 1.92, p < .14$ . As a result, type of cancer was not controlled in regression analyses examining predictors of quality of life.

Children included in this study also varied with regard to the amount of time since diagnosis. Based on previous findings with regard to differences in quality of life ratings as a function of time since diagnosis, the relationship between the time since diagnosis and quality of life was examined using correlational analyses. Time since diagnosis was related significantly to

maternal quality of life ratings ( $r = .34, p < .03$ ) but not to paternal ( $r = .30, p < .28$ ) or child ( $r = .12, p < .63$ ) quality of life ratings. As a result, time since diagnosis was controlled in regression analyses examining mothers' quality of life ratings.

Children in this study also varied in age. Correlational analyses examining the relationship between children's age and quality of life ratings were performed. Children's age was not related significantly to quality of life ratings provided by mothers ( $r = -.17, p < .26$ ), fathers ( $r = -.39, p < .14$ ), or children ( $r = .08, p < .75$ ). As a result, children's age was not controlled in the regression analyses examining predictors of quality of life.

### *Predicting Children's Quality of Life*

In examining the predictors of children's quality of life for mothers, hierarchical regression was used to control for time since diagnosis. Time since diagnosis was entered in step one, and mothers' characteristics were entered in step two. For step one, time since diagnosis predicted mothers' ratings of their children's quality of life,  $F(1, 40) = 4.67, p < .04$ . When mothers' characteristics (i.e., depression, anxiety, and parenting stress) were entered in step two, the regression analysis remained significant,  $F(4, 37) = 3.70, p < .01$ . Results are presented in Table 2.

In examining the predictors of children's quality of life for fathers, hierarchical regression was used to control for participant site. Site was entered in step one, and fathers' characteristics were entered in step two. For step one, site predicted fathers' ratings of their children's quality of life,  $F(1, 14) = 4.93, p < .04$ . The discrepancy between the number of participants at each site ( $n = 3$  vs.  $n = 13$ ) hinders the significance of this finding, however. When fathers' characteristics (i.e., depression, anxiety, and parenting stress) were entered, the

regression equation remained significant,  $F(4, 11) = 5.17, p < .01$ , with site again accounting for a significant portion of the variance. Results are presented in Table 3.

In examining the predictors of children's own quality of life ratings, hierarchical regression was used with psychological characteristics (e.g., anxiety, depression, internalizing behavior problems, and externalizing behavior problems) entered in step one and physical symptoms (i.e., scores from symptoms checklist) entered in step two. For step one, children's psychological characteristics predicted their ratings of their own quality of life,  $F(4, 12) = 4.22, p < .02$ , with externalizing behavior problems accounting for a significant portion of the variance. When children's physical symptoms were entered in step two, the regression equation remained significant,  $F(5, 11) = 3.31, p < .05$ . Results are presented in Table 4.



## CHAPTER FOUR: DISCUSSION

Quality of life has become an important factor in the treatment of pediatric cancer. Due to increased survival rates, children are dealing with the psychological impact of cancer in addition to the side effects of their treatment protocols. Areas of concern for assessing quality of life include who is able to provide the most accurate report and what factors will affect the validity of the report. Given the importance of this construct, this study examined the relationships among ratings of quality of life, parental characteristics, and child characteristics in families with a child who had been diagnosed with cancer.

Research findings from studies examining the concordance of ratings of quality of life provided by children who have been diagnosed with cancer and those provided by their parents have suggested that concordance is low and that parental ratings may be overestimating the impact of cancer on children and adolescents (Boggs & Durning, 1998; Levi & Drotar, 1999; Parsons et al., 1999; Sawyer et al., 1999; Vance, 2001). Research investigating reasons for this low concordance has suggested that different factors may be involved (e.g., an interaction between the amount of time since the child received treatment and the direction of the disagreement, bias in parental ratings related to the psychological distress of the parent). The purpose of the current study was to further examine this relationship to address the complications associated with obtaining accurate quality of life ratings.

Regarding the first hypothesis of this study, mothers' ratings of their children's quality of life were correlated positively and significantly with both fathers' and children's ratings of quality of life. Further, mothers' ratings were not significantly different from those provided by fathers and by their children. This finding is contrary to those of previous studies, in which low concordance has been found between parental and child ratings of children's quality of life (Levi

& Drotar, 1999; Sawyer et al., 1999). This difference may be related to the use of a cancer specific quality of life measure in this study. It may be that cancer-specific symptoms are discussed more between parents and their children than are general symptoms, especially at a time when the child is visiting the doctor's office and more attention is being focused on the child's cancer diagnosis.

In examining the relationship between parental characteristics and quality of life ratings, it was found that increased symptoms of depression, anxiety, and parenting stress in mothers were all related to their own decreased ratings of their children's quality of life. Thus, it appears that higher levels of maternal psychological distress are related to poorer quality of life ratings for children. This finding may be related to a bias in the mothers' ratings due to their own symptoms, or it may be that having a child with a poorer quality of life leads to higher levels of psychological distress. Overall, this finding is consistent with the literature, which has suggested that parental psychological symptoms are related to a tendency to report higher levels of psychological problems in children (Fergusson et al., 1993; Mick et al., 2000; Moretti et al., 1985). In contrast, only paternal anxiety was related significantly to paternal ratings of children's quality of life. It should be noted, however, that paternal depression and parenting stress were related to paternal ratings of quality of life in the expected way. A low number of fathers participating in this study may have led to the lack of significance of these relationships. Thus, the hypothesis regarding the relationship between parental psychological symptoms and parental ratings of quality of life was only supported partially.

With regard to the relationship between parental and child characteristics, children's characteristics were not found to be related significantly to their mothers' characteristics; however, a significant positive relationship was found between children's ratings of their own

depression and fathers' parenting stress. It may be that having a child with a physical illness who also is experiencing emotional difficulties leads to greater involvement in parenting tasks from the father, whereas mothers, who typically are the primary caretakers (Bryant & Zick, 1996), do not experience a greater burden due to increased involvement from the child's father.

With regard to the relationship between children's self-report of their own characteristics and quality of life, children's ratings of their own quality of life were related significantly to their own depression, internalizing behavior problems, and physical symptoms. These results suggest that, in addition to the physical symptoms that may be noticed easily by others, children's psychological symptoms are related to their quality of life. Given the relationships among these variables, the use of psychological services, in addition to the medical treatments that children diagnosed with cancer receive, may be an important adjunct to improving quality of life.

Finally, in predicting quality of life ratings, the results of this study suggested that time since diagnosis and mother's characteristics predicted significantly their ratings of their children's quality of life. This finding is consistent with the hypothesis that higher levels of psychological symptoms in mothers lead to poorer ratings of children's quality of life and with similar findings in the literature regarding mothers' ratings of emotional and behavioral functioning in their children and adolescents. This finding is also consistent with the finding that parents report higher scores in quality of life over time (Parsons et al., 1999). This finding has important practical implications. It may be the case that, when mothers are experiencing psychological symptoms, the ratings that they provide regarding their children's quality of life may not be an accurate assessment of how their children are actually doing. Rather, these ratings may be a reflection of how the mothers are doing. In addition, mothers may be focusing only on

the short-term effects of cancer and its treatment and, therefore, may not be an accurate reporter of their children's quality of life over time.

With regard to fathers, participant site and their characteristics predicted their ratings of their children's quality of life, with site accounting for a significant proportion of the variance. The number of participants for each site hinders the significance of this finding, however. The low number of fathers who participated in this study may have led to the lack of significant findings with regard to fathers' characteristics. As a result, future studies examining quality of life in children who have been diagnosed with cancer should work to include fathers so that the relationship between paternal characteristics and paternal ratings of quality of life can be understood further.

Finally, children's psychological and physical symptoms predicted significantly their ratings of their own quality of life. This finding suggested that children who experience psychological as well as physical difficulties tend to rate themselves as having a lower quality of life. Given this finding, it may be beneficial for medical staff to be aware of the psychological symptoms exhibited by children and adolescents, in addition to their physical symptoms. With this awareness, medical staff can refer these children and adolescents for psychological services as appropriate so that they may make further improvements in their quality of life.

Overall, the link between parental and child characteristics and quality of life ratings in this study suggested that these families may benefit from psychological interventions. Future research needs to examine the relationship between these variables and the effects of psychological intervention on the quality of life of children and adolescents diagnosed with cancer. Further, a directional investigation into the relationship between parental characteristics and the quality of life of children and adolescents diagnosed with cancer would allow for a better

understanding of this relationship and how psychological interventions may be used to improve quality of life. Given the link between parenting stress in fathers and depression in children, a more in depth examination of parent-child relationships within families dealing with chronic medical conditions is warranted so that a better understanding of how family members relate under such adverse conditions can be achieved. In addition, there is an overall lack of research including fathers in the current field of study. Investigating the father's role in families who are dealing with a child or adolescent who has been diagnosed with cancer may be important in keeping everyone in the family "psychologically healthy" and increasing the amount of support that the child receives. Finally, an investigation into the causal factors between quality of life and treatment outcome may help us to better understand how to treat those with pediatric cancer and create ways of avoiding the adverse effects that pediatric cancer has on the entire family.

Limitations to the current study include a poor response rate (31% for mothers, 11% for fathers, and 13% for children). Although unknown, the decreased response rates of fathers may have been related to the lower incidence of attendance at children's doctor appointments. In addition, many of the children within the families who were approached for participation were excluded from the study based on their age. The low response rate in this study may affect its external validity, decreasing the generalizability of the results to the intended population. Some of the relationships found significant for mothers were approaching significance for fathers. Thus, it is possible that, given a higher number of fathers, these correlations also may have reached significance. Finally, lack of diversity in the sample studied (i.e., the families in this study were predominantly Caucasian, all families were living in the same general location in one southeastern state, the children had a higher proportion of Leukemia diagnoses) also may decrease the generalizability of the findings of this study.

In summary, high concordance was found between the ratings of mothers and fathers, as well as between the ratings of mothers and their children, when examining the quality of life experienced by children and adolescents diagnosed with cancer. In addition, increased symptoms of anxiety in mothers and fathers, as well as increased symptoms of depression and parenting stress in mothers, were related significantly to lower ratings of quality of life for their children. Further, depressive symptoms in children were related to parenting stress in fathers. Children's depressive symptoms, internalizing behavior problems, and physical symptoms also were related to ratings of their own quality of life. Finally, informants' ratings of quality of life were predicted collectively by their characteristics. Overall, these findings suggest the importance of determining the need for psychological interventions for all family members when a child or adolescent has been diagnosed with cancer. Improvements in the overall functioning of all family members may lead to a better quality of life for the diagnosed child.

## APPENDIX

### TABLES

Table 1. Correlational Analyses for Informants' Characteristics and Quality of Life Ratings

	1	2	3	4	5	6	7	8	9	10	11	12	13	14
<i>Mothers</i>														
1. QOL	-													
2. BDI	-.38**	-												
3. BAI	-.49**	.63**	-											
4. PSI	-.31*	.23	.29	-										
<i>Fathers</i>														
5. QOL	.72**	-.53	-.87**	-.46	-									
6. BDI	-.78**	.64*	.81**	.47	-.49	-								
7. BAI	-.77**	.52	.79**	.33	-.59*	.84**	-							
8. PSI	-.30	.24	.40	.76**	-.46	.58*	.49	-						
<i>Children</i>														
9. QOL	.71**	-.40	-.46	-.23	.36	-.92*	-.96*	.07	-					
10. CDI	-.38	.22	.24	.34	-.08	.46	.33	.97**	-.67*	-				
11. RCMAS	.04	-.01	.12	.19	.79	-.42	-.45	.35	-.34	.49*	-			
12. Int.Prob.	-.13	.12	.17	.44	-.07	.22	.06	.92*	-.54*	.78**	.62**	-		
13. Ext.Prob.	.17	-.11	.07	.51*	-.02	-.03	-.15	.93*	.12	.20	.44	.58*	-	
14. Symptom	-.33	.40	.12	.47	-.13	.02	-.14	.82	-.52*	.67**	.40	.56*	.01	-
Note. * $p < .05$ ** $p < .01$														



Table 2. Regression Analyses for Maternal Characteristics Predicting Children's Quality of Life

<i>Variable</i>	<i>SE B</i>	<i>β</i>	<i>t</i>
Step 1. $F(1, 40) = 4.67, p < .04, R^2 = .11$			
Time Since Diagnosis	.14	.32	2.16*
Step 2. $F(4, 37) = 3.70, p < .01, R^2 = .29, R^{2\Delta} = .18$			
Time Since Diagnosis	.13	.19	1.27
Depression	.44	-.12	-.10
Anxiety	.51	-.39	-1.89
Parenting Stress	.11	-.11	-.75
<i>Note.</i> * $p < .05$			

Table 3. Regression Analyses for Paternal Characteristics Predicting Children's Quality of Life

<i>Variable</i>	<i>SE B</i>	<i>β</i>	<i>t</i>
Step 1. $F(1, 14) = 4.93, p < .04, R^2 = .26$			
Participant Site	12.60	.51	2.22*
Step 2. $F(4, 11) = 5.17, p < .01, R^2 = .65, R^{2\Delta} = .39$			
Participant Site	11.37	.60	2.88*
Depression	.89	-.30	-.79
Anxiety	.91	-.06	-.17
Parenting Stress	.22	-.36	-1.62
<i>Note.</i> * $p < .05$			

Table 4. Regression Analyses for Children's Characteristics Predicting Children's Quality of Life

<i>Variable</i>	<i>SE B</i>	<i>β</i>	<i>t</i>
Step 1. $F(4, 12) = 4.22, p < .02, R^2 = .58$			
Depression	.74	-.15	-.43
Anxiety	.57	-.06	-.23
Internalizing	.74	-.74	-1.75
Externalizing	.51	.61	2.26*
Step 2. $F(5, 11) = 3.31, p < .05, R^2 = .60, R^{2\Delta} = .02$			
Depression	.82	-.05	-.13
Anxiety	.59	-.04	-.15
Internalizing	.76	-.71	-1.62
Externalizing	.54	.55	1.91
Symptoms	.67	-.18	-.67
<i>Note.</i> * $p < .05$			

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